

Ethics briefings

Female genital mutilation

Female genital mutilation generates passionate argument about child abuse and the limits of cultural independence. The Sudanese Women's Rights Group (SWRG), which is based in the United Kingdom (UK) issued a press release expressing grave concern about the Sudanese government's intention to legalise female genital mutilation (circumcision) (Sudanese Women's Rights Group press release *Legalisation of female circumcision in Sudan*, 18 June 2002). The Sudanese Ministry of Religious Affairs and Endowment, together with an Islamic university, held a workshop entitled *Towards the Legalisation of Female Circumcision & Establishment of Training Centers for Operators* (excisors). It recommended that female circumcision should be legalised, awareness about its importance in society should be raised, and the Islamic University should establish centres all over the country for training practitioners of female circumcision. The SWRG is concerned about the strong support for the recommendations among government officials, in a country where 89% of women have been mutilated.¹

The Sudanese government's actions came just a few months before female genital mutilation was rejected at a 190 country strong world summit.² The summit agreed that health care services must "conform to basic human rights and fundamental freedoms", a provision designed to prevent female genital mutilation. Around the same time the American embassy in Nairobi said that Somali refugees who had rushed to circumcise their daughters before being moved to the US would probably be barred from emigrating.³ The statement prompted fierce debate, and the US later backtracked.⁴

Recent debate in the UK focused on taking young girls abroad for mutilation. Nothing in UK law specifically prohibits families from taking daughters abroad for female genital mutilation, but doctors must consider what

action they should take to protect a child at risk of being mutilated. The government is exploring ways to strengthen the Prohibition of Female Circumcision Act 1985 in this regard.

Access to health records

Patients in the UK are entitled to see and have copies of their health records. Currently, however, legislation that gives patients access has some significant restrictions. If the doctor responsible for the patient's care believes that disclosing anything in records would cause significant harm to the patient or another person, it may be withheld. Similarly, if records contain information that relates to an identifiable third party, such as a family member, that information may not be released without the third party's consent.

Proposals to remove these restrictions would allow patients to see anything in their notes. France moved to such a scheme in 2001. France's secretary of state for health claimed that allowing open access made patients more active participants in health care, and no longer the passive objects of medical decisions.⁵ Some French doctors and members of parliament opposed the move, however, because of risks to patients' health. Patient groups in the UK see doctors' "secret purging" of records as detrimental to cooperation and mutual trust. Knowing that doctors can decide to withhold certain information leads some patients to worry about inappropriate censorship. Some doctors in the UK also argue that patients should be entitled to see everything in their notes, and that removing the requirement for doctors to review records before they are disclosed would free up significant resources.

Despite the clear benefits such as greater trust and understanding resulting from patients seeing their full records, doctors are often concerned at the possible risks of unfettered access. It should be rare that records contain information that may cause harm, but if they do, the consequences of open access would be grave. Doctors are also concerned about their freedom to record information about patients' family members if the records are open access. General practitioners (GPs) might make a note of the fact that a

patient's relative has been diagnosed with a genetic condition. The GP knows this because the relative is a patient too, but the relative wants privacy. Notes of this kind can be a useful prompt when the patient presents with possible early signs of the same condition.

Many issues have to be balanced in this context: firstly, whether doctors have a duty to prevent avoidable harm, and their liability if they fail to do so; secondly, how to manage doctors' duty of confidentiality to third parties (who might be their patients) and their ability to make notes that might enhance patient care; thirdly, whether giving unrestricted access to patients would improve the doctor/patient relationship, and fourthly, whether the benefits, including the time saved by not having to "weed" records, outweigh any risks.

In England and Wales the Department of Health has a review group, with representatives of patient and professional organisations, looking at these issues.

It is also looking at the use of information about patients' family histories. Such information is central to much of health care, particularly clinical genetics. Under data protection legislation, anybody who holds data about identifiable individuals must provide those individuals with information about the data processing, including the identity of the data controller, and the purpose of the processing. But a patient who tells a genetics clinic that his father had a genetic condition might not want his father to know that he has approached a genetics clinic.

Australia solved this problem by making a public interest declaration that allowed health service providers to collect health information about third parties without their consent or knowledge. It applies only to family history information needed for the patient's diagnosis, care, or treatment. Australia's Privacy Commissioner consulted about extending the provisions, and proposed renewing the declaration for a further five years (Federal Privacy Commissioner press release *Announcement: two public interest determinations, relating to the health sector*, have been tabled in parliament, 17 October 2002). The UK is considering making an order to exclude or

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make special provision for family history data in relation to these processing requirements, so doctors are not discouraged from taking a family history. (See: Symposium on consent and confidentiality pages 2–40.)

Mental health

As predicted in previous Ethics Briefings,⁶ summer 2002 saw the publication of draft mental health bills for England and Scotland. But fierce opposition on civil liberties' grounds, including from the BMA, appears to have stalled the progress of the English bill. It is too early to say to what extent these concerns will be addressed in any redrafting, but for the sake of debate about future change it is useful to note some of the more contentious areas.

It is interesting to compare the draft English and Scottish bills since the latter did not meet the chorus of complaint that greeted its English counterpart. They were similar in some ways; both sought to provide a legal structure for non-consensual treatment for mental disorder, including in the community, and both sought to bring the legislation in line with the European Convention on Human Rights. The English draft bill, however, was much more focused on controlling the risk posed to the public by violent patients, in particular those said to be suffering from, in the government's words, "dangerous and severe personality disorder".

Many areas in the English bill sparked controversy amongst doctors and ethicists. Firstly, the removal of the "treatability criterion" from the 1983 act, and the replacement of its tripartite definition of mental disorder with a single, catchall definition. It defined mental disorder as "any disability or disorder of mind or brain which results in an impairment or disturbance of mental functioning". This would bring individuals with "untreatable" personality disorder within the reach of compulsory powers. If they are indeed untreatable, and not responsive to psychiatric treatment, arguably the role of any compulsory powers is no longer therapy but

control of antisocial individuals. Doctors are concerned that this could upset the careful balance of the liberty and autonomy of patients with the need to provide compulsory treatment.

The draft English bill has also removed a feature of the previous legislation that prohibits the use of compulsion with patients deemed incompetent "by reason of promiscuity or other immoral conduct, sexual deviancy or dependence on alcohol or drugs". The motive behind removing clauses that were once regarded as a necessary corrective to charges of medical "moralism" has been questioned. The Law Society is concerned that the intention is to use the legislation to deal with paedophiles, who, in its view, would be better dealt with under criminal law.⁷

Under the new bill, decisions about compulsion could be made by health professionals alone, since the requirement to involve an approved social worker was removed. This could mean that all professionals involved in the initial assessment are from the same hospital or trust. This raises serious questions about independence.

More positively, the English draft contained interesting new safeguards which it is hoped will become law. It proposed a new Mental Health Tribunal to authorise all compulsory treatment beyond 28 days. It also contained safeguards for informal patients with long term incapacity who cannot consent to treatment but who are not resisting it. These include the appointment of a nominated person to act on their behalf, treatment on the basis of an agreed care plan, access to specialist advocacy, and the right to challenge admission and treatment before the Mental Health Tribunal. It proposed giving patients access to a new specialist "mental health advocacy service".

By comparison, the Scottish bill has a more principled approach to compulsory powers and appears much more balanced in its attempt to reconcile compulsion with respect for patients' autonomy. It retains a multiform definition of mental disorder, the three categories being mental illness, learning disability, and personality disorder. The statement of principles acknowledges that the last two of these groups

of patients have very different needs and should receive treatment appropriate to them. It also acknowledges that these two groups have been left in "for the time being", and that their inclusion is to be reviewed. The bill also retains the specific exclusions relating to sexual orientation or behaviour, and alcohol or substance misuse. Its provisions would substantially replace the role of the sheriff in mental health legislation with a new Mental Health Tribunal.

A great step forward in the Scottish bill is the proposal to allow carers or service users to request an assessment when a person's condition is deteriorating, but does not yet warrant intervention under the act. This addresses longstanding concerns about distress caused by having to wait until a sufferer's condition has become critical. Such an approach would be welcomed in England too. The Scottish bill also acknowledges the heterodox nature of modern relationships, replacing the "nearest relative" with a "named person" who has the right to apply for, appear, and be represented at tribunal hearings on behalf of the patient.

Concern about the English bill united medical, legal, and mental health user groups in a chorus of opposition. To avoid future conflict, future drafts must be more attentive both to the civil liberties of a very vulnerable group, and to the integrity of the therapeutic relationship.

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References

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- 7 **The Law Society.** *The draft Mental Health Bill 2002: The Law Society's submission to the Health and Social Services Committee of the National Assembly for Wales.* London: The Law Society, 2002: 18.